#### \$~1 & 21 to 48

## \* IN THE HIGH COURT OF DELHI AT NEW DELHI

+ CONT.CAS(C) 722/2022 INSHA MINOR THROUGH HER NEXT FRIEND AND NATURAL FATHER SH.IRSHAD AHMAD SOFI..... Petitioner

Through: Mr.Ashok Agarwal, Mr.Kumar

Utkarsh and Mr. Manoj, Advs.

versus

DR D K SHARMA ..... Respondent

Through: Mr. Tanveer Oberoi, Adv. for AIIMS.

Mr.Balendu Shekhar, CGSC with Mr.Krishna Chaitanya and Mr.Raj

Kumar Maurya, Advs. for R-2.

+ CONT.CAS(C) 415/2022 & CM APPL. 18280/2022

MASTER MEDHANSH JHAWAR @ MADHAV THROUGH HIS

NATURAL GUARDIAN ..... Petitioner

Through: Ms. Shyel Trehan, Amicus Curie [M.

No. 098101638181 with Mr. Rohan

Poddar Adv.

versus

RAJESH BHUSHAN & ORS. ..... Respondents

Through: Mr.Jaswinder Singh, Adv. for R-1.

Mr.Chetan Sharma, ASG with Mr.Ripu Daman Bhardwaj, CGSC and Ms.Aakriti Roy, Adv. for UOI. Mr.Tanveer Oberoi, Adv. for AIIMS.

22

+ W.P.(C) 1182/2022, CM APPL. 3442/2022 (Direction)

INSHA MINOR THROUGH HER NEXT FRIEND AND NATURAL FATHER SH IRSHAD AHMAD SOFI ..... Petitioner

Through: Mr.Ashok Agarwal, Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs.

Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.

versus

UNION OF INDIA & ORS.

..... Respondents

Through:

Mr. Sanjeev Uniyal, Mr. Dhawal Uniyal, Mr. Sachin Chandela, Advs.

for UOI.

Mr. Tanveer Oberoi, Adv. for AIIMS. Mr. Rishikesh Kumar, ASC, GNCTD with Mr.Muhammad Zaid and Ms.

Sheenu Priya, Advs. for R-4.

23

+ W.P.(C) 322/2021, CM APPL. 812/2021(Direction)
KESHAV SHARMA AGE 12 YEARS THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SANJEEV KUMAR

..... Petitioner

Through:

Mr.Ashok Agarwal, Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ANR.

..... Respondents

Through:

Mr. Chetan Sharma, ASG with

Mr.Ajay Digpaul, CGSC, Mr.Kamal Digpaul, Ms.Swati Kwatra and

Mr.Anil Gupta, Advs. for UOI.

Mr. Tanveer Oberoi, Adv. for AIIMS.

24

+ W.P.(C) 1491/2021, CM APPL. 4291/2021(Direction) CM APPL. 8671/2022(Direction)

MASTER MEDHANSH JHAWAR @ MADHAV..... Petitioner

Through: Mr. Rahul Malhotra, Mr. Manas

Tripathi and Mr. Anshul Gupta, Advs. Ms. Shyel Trehan, Amicus Curie [M.

No. 09810163818]	with Mr.	Rohan
Poddar Adv.		

versus

UNION OF INDIA & ANR. ..... Respondents
Through: Mr.Tanveer Oberoi, Adv. for AIIMS.

25

+ W.P.(C) 1511/2021, CM APPL. 4331/2021(Direction) CM APPL. 8616/2022(Direction)

MASTER KENIT JHAWAR @ KESHAV ..... Petitioner

Through: Mr. Rahul Malhotra, Mr. Manas

Tripathi and Mr. Anshul Gupta, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ANR. ..... Respondent

Through: Mr.Ghanshyam Mishra, Ms.Sunaina

Mishra, Mr.Rishav Dubeyand Mr.Sameer Sharma, Advs. for UOI. Mr.Tanveer Oberoi, Adv. for AIIMS.

26

+ W.P.(C) 1611/2021, CM APPL. 4600/2021(Direction)
LAKSHYA KUMAR GOYAL, 8 YRS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. VIPIN KUMAR

..... Petitioner

Through: Mr.Ashok Agarwal, Mr.Kumar

Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ANR. ..... Respondent

Through: Ms. Shyel Trehan, Amicus Curie [M.

No. 09810163818] with Mr. Rohan

Poddar Adv.

Mrs.Bharathi Raju, Sr. Panel Counsel

for R-1.

Mr. Tanveer Oberoi, Adv. for AIIMS.

27

+ W.P.(C) 5315/2020, CM APPL. 19189/2020(Direction)

MASTER ARNESH SHAW

..... Petitioner

Through: Mr. Ral

Mr. Rahul Malhotra, Mr. Manas Tripathi and Mr. Anshul Gupta, Advs.

Mr. Asif Ahmed, Adv.

Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

Through:

UNION OF INDIA & ANR.

..... Respondents

Mr.Chetan Sharma, ASG with

Mr.Ripu Daman Bhardwaj, CGSC

for UOI.

Mr. Tanveer Oberoi, Adv. for AIIMS.

28

+ W.P.(C) 3662/2021, CM APPL. 11103/2021, CM APPL. 25590/2021(Direction), CM APPL. 32504/2021

PAYEL BHATTACHARYA

..... Petitioner

Through:

Mr.Shivam, Mr.Aditya Chatterjee,

Mr. Abhishek Singh, Advs.

Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ORS.

..... Respondent

Through: Mr.Chetan Sharma, ASG with

Mr.Ripu Daman Bhardwaj, CGSC

for UOI.

Mr. Anuj Agarwal, ASC with

Ms. Ayushi Bansal, Adv. for R-2 Mr. Tanveer Oberoi, Adv. for AIIMS. + W.P.(C) 3682/2021, CM APPL. 11153/2021(Direction)
HARSHIT SONI, 16 YEARS OLD, THROUGH HIS NEXT
FRIEND AND NATURAL FATHER SH. TIKAM CHAND SONI

..... Petitioner

Through: Mr.Ashok Agarwal, Mr.Kumar

Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ANR. ..... Respondent

Through: Mr.Chetan Sharma, ASG with Mr. T. P. Singh, Sr. central govt. counsel for

UOI.

Mr. Tanveer Oberoi, Adv. for AIIMS.

**30** 

+ W.P.(C) 3689/2021, CM APPL. 11179/2021(Direction)
DHANANJAY BHARDWAJ, 11 YEARS OLD, THROUGH HIS
NEXT FRIEND AND NATURAL FATHER SH. AMIT KUMAR

..... Petitioner

Through: Mr.Ashok Agarwal, Mr.Kumar

Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ANR. ..... Respondent

Through: Mr.Sanjeev Uniyal, Mr.Dhawal

Uniyal, and Mr.Sachin Chandela,

Advs. for UOI.

Mr. Tanveer Oberoi, Adv. for AIIMS.

31

+ W.P.(C) 3706/2021, CM APPL. 11229/2021(Direction)
KHUSHWANT BHARDWAJ, 7 YEARS OLD, THROUGH HIS
NEXT FRIEND AND NATURAL FATHER SH. NIKHIL

	Through:	Mr.Ashok Agarwal, Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.
<b>32</b> +	versus UNION OF INDIA & ANR. Through:  W.P.(C) 3707/2021, CM APPI AARAV GARG, 5 YEARS OF	Respondent Mr.Tanveer Oberoi, Adv. for AIIMS.  2. 11230/2021(Direction) LD, THROUGH HIS NEXT FRIEND
	AND NATURAL FATHER SI Through:	H. VIVEK Petitioner Mr.Ashok Agarwal, Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.
	versus UNION OF INDIA & ANR. Through:	Respondents Mr. Sidharth Khatana, Adv. for R-1. Mr.Tanveer Oberoi, Adv. for AIIMS.
33 +	W.P.(C) 3729/2021, CM APPI MANISH, 8 YEARS OLD, TH NATURAL FATHER SH. PHO Through:	IROUGH HIS NEXT FRIEND AND
	versus UNION OF INDIA & ANR. Through:	Respondents Mr.Tanveer Oberoi, Adv. for AIIMS.

BHARDWAJ

..... Petitioner

1	4
. 1	4

W.P.(C) 3737/2021, CM APPL. 11277/2021(Direction) +SHOURYA MARU, 7 YEARS OLD, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. KAMAL KUMAR **MARU** ..... Petitioner Agarwal. Mr.Kumar Through: Mr.Ashok Utkarsh and Mr.Manoi Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv. versus UNION OF INDIA & ANR. ..... Respondent Mr.Ranvir Singh, CGSC for UOI. Through: Mr. Tanveer Oberoi, Adv. for AIIMS. 35 W.P.(C) 3859/2021, CM APPL. 11647/2021(Direction) +SIDDHARTH SWARNKAR, 9 YEARS OLD, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. DINESH KUMAR **SWARNKAR** ..... Petitioner Agarwal, Through: Mr.Ashok Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 098101638181 with Mr. Rohan Poddar Adv. versus UNION OF INDIA & ANR. ..... Respondent Mr. Tanveer Oberoi, Adv. for AIIMS. Through: **36** W.P.(C) 4045/2021, CM APPL. 12213/2021(Direction) +UTKARSH INDRAJIT PAWAR, 10 YEARS OLD, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. INDRAJIT DAMAR PAWAR ..... Petitioner Through: Mr.Ashok Agarwal, Mr.Kumar

> Utkarsh and Mr. Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

# Poddar Adv.

	versus	
	UNION OF INDIA & ANR.	Respondent
	Through:	Mr. Harish Kumar Garg, Adv. for R-1
		Mr. Tanveer Oberoi, Adv. for AIIMS.
<b>37</b>		
+	W.P.(C) 4067/2021, CM APP	L. 12306/2021(Direction)
		HROUGH HIS NEXT FRIEND AND
	•	ARENDRA KUMAR YADAV
		Petitione
	Through:	Mr.Ashok Agarwal, Mr.Kuma
	Ç	Utkarsh and Mr. Manoj Kumar, Advs.
		Ms. Shyel Trehan, Amicus Curie [M.
		No. 09810163818] with Mr. Rohan
		Poddar Adv.
	versus	
	UNION OF INDIA & ANR.	Respondents
	Through:	Mr.Sanjeev Sabharwal, Sr. govt
		counsel for UOI.
		Mr. Tanveer Oberoi, Adv. for AIIMS.
38		,
+	W.P.(C) 4259/2021, CM APP	L. 12948/2021(Direction)
		THROUGH HIS NEXT FRIEND AND
	NATURAL FATHER SH. RA	
	Through:	Mr.Ashok Agarwal, Mr.Kuma
	Ç	Utkarsh and Mr. Manoj Kumar, Advs.
		Ms. Shyel Trehan, Amicus Curie [M.
		No. 09810163818] with Mr. Rohan
		Poddar Adv.
	versus	
	UNION OF INDIA & ANR.	Respondents
	Through:	Mr. Tanveer Oberoi, Adv. for AIIMS.
39	Ç	,
+	W.P.(C) 4304/2021, CM APP	L. 13108/2021(Direction)
	` '	S OLD, THROUGH HIS NEXT
	-	ATHER SH. AMIT HANDOO

Through:	Petitioner Mr.Ashok Agarwal, Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.
versus	
UNION OF INDIA & ANR.	Respondent
Through:	Mr.Satya Ranjan Swain, Sr. Panel Counsel with Mr.Kautilya Birat, Adv. for UOI.
	Mr. Tanveer Oberoi, Adv. for AIIMS.
•	L. 13949/2021(Direction) RS OLD, THROUGH HIS NEXT ATHER SH. SATBIR DAHIYA Petitioner
Through:	Mr.Ashok Agarwal, Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.
versus	
UNION OF INDIA & ANR.	Respondent
Through:	Mr.Avnish Singh, Sr. central govt. counsel for UOI with Mr.Syed Mohd. Muztaba, Adv.

41

40

W.P.(C) 4812/2021, CM APPL. 14844/2021(Direction) +NIKHIL YOGENDERSINGH CHOUDARY, 17 YEARS OLD, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. YOGENDERSINGH P CHOUDARY ..... Petitioner

Through: Mr.Ashok Agarwal, Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Mr. Tanveer Oberoi, Adv. for AIIMS.

### Poddar Adv.

42	versus UNION OF INDIA & ANR. Through:	Respondent Mr.Ranvir Singh, CGSC for UOI. Mr.Tanveer Oberoi, Adv. for AIIMS.
+	W.P.(C) 5394/2021, CM APPI UDAYVEER SINGH GULER	L. 16683/2021(Direction) IA, 7 YEARS OLD, THROUGH HIS
	NEXT FRIEND AND NATU	•
	GULERIA	Petitioner
	Through:	Mr.Ashok Agarwal, Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan Poddar Adv.
	versus	
	UNION OF INDIA & ANR.	Respondent
	Through:	Mr. Tanveer Oberoi, Adv. for AIIMS.
<b>43</b> +	W.P.(C) 5395/2021, CM APPI MASTER AYUSHMAN CHA Through:	TURVEDI Petitioner

versus

UNION OF INDIA & ORS. ..... Respondent

Through: Mr.Niraj Kumar, Sr. Central Govt.

Counsel for R-1/UOI.

Mr. Farman Ali, Sr. Panel counsel and Ms.Usha Jamnal, Adv. for R-1. Ms.Moksha Sharma, Ms.Varsha Sharma, Advs. for Mr.Jawahar Raja,

ASC (C) for R-2.

44

+ W.P.(C) 9684/2021

# AADHYAN JAISWAL 11 YEARS OLD THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH ANIL KUMAR JAISWAL

..... Petitioner

Through: Mr.Ashok Agarwal, Mr.Kumar

Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ORS. ..... Respondent

Through: Mr.Chetan Sharma, ASG with

Mr.Ripu Daman Bhardwaj, CGSC with Mr.Kushagra Kumar, Adv. for

UOI.

Mr.Divyam Nandrajog, Panel counsel for GNCTD with Mr.Jasmeet Jolly,

Adv. for R-2.

Mr. Tanveer Oberoi, Adv. for AIIMS

45

+ W.P.(C) 14317/2021, CM APPL. 45148/2021(Direction) SHREYANSH AARAV, 11 YEARS OLD, THROUGH HIS NEXT FRIEND AND NATURAL MOTHER SMT. KANCHAN KAMINI

..... Petitioner

Through: Mr.Ashok Agarwal, Mr.Kumar

Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ANR.

..... Respondents

Through: Mr.Chetan Sharma, ASG with

Mr.Ripu Daman Bhardwaj, CGSC for

UOI.

	Mr.Tanveer Oberoi	, Adv. for AIIMS
W.P.(C) 2943/2020, CM APPI	L. 6633/2022(Direction	on)
ALISHBA KHAN		Petitioner

Through: Mr. Rahul Malhotra, Mr. Manas

Tripathi and Mr. Anshul Gupta, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA AND ORS.

..... Respondent

ASC Through: Mr.Anui Agarwal, with Ms. Ayushi Bansal, Adv. for R-2 & R-

4.

Mr. Tanveer Oberoi, Adv. for AIIMS.

47

46

+

W.P.(C) 10782/2020, CM APPL. 33828/2020(Direction) +AVIRAJ GARG, AGE 4 YEARS, THROUGH HIS NEXT FRIEND AND NATURAL FATHER SH. ABHINAV GARG ..... Petitioner

> Agarwal, Through: Mr.Ashok Mr.Kumar Utkarsh and Mr.Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M.

> > No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA & ANR. ..... Respondent

> Mr. Tanveer Oberoi, Adv. for AIIMS. Through:

48

W.P.(C) 11610/2017, CM APPL. 27637/2018 (Direction) +

FSMA INDIA CHARITABLE TRUST ..... Petitioner

> Agarwal, Mr.Ashok Mr.Kumar Through:

Utkarsh and Mr. Manoj Kumar, Advs. Ms. Shyel Trehan, Amicus Curie [M. No. 09810163818] with Mr. Rohan

Poddar Adv.

versus

UNION OF INDIA AND ANR.

..... Respondent

Through: Mr.Chetan Sharma,

ASG with

Mr. Vijay Joshi, Sr. panel counsel, Mr. Gurjas Sigh Narula, Adv. for R-1.

Mr.Sameer Vashisht, ASC (civil) GNCTD with Ms.Sanjana Nangia,

Adv.

Mr. Tanveer Oberoi, Adv. for AIIMS.

### **CORAM:**

#### HON'BLE MR. JUSTICE YASHWANT VARMA

### ORDER 05.08.2022

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- 1. The Court is firstly apprised that the Special Leave Petition which was taken against the order of 14 December 2021 came to be disposed of on 11 July 2022 with the Supreme Court observing that it found no reason to entertain the challenge and that liberty stood reserved to the Union to advance submissions before this Court in the pending batch. That order has also noticed the last order passed by the Court on 01 June 2022.
- 2. The Court notes that in its last order it had requested the learned Amicus Curiae to contact Dr. Apurba Ghosh and Dr. Arun Shastry, two eminent doctors, who were carrying on research in the field of rare diseases to attend these proceedings. Pursuant to that request, Dr. Shastry has graciously appeared. Dr. Ghosh could not attend these proceedings on account of personal difficulties.
- 3. The Court is informed that M/s Dystrophy Annihilation Research Trust has developed a drug for the treatment of Duchenne Muscular Dystrophy [DMD]. It had sought and has been granted the requisite statutory permission to undertake clinical trials of that drug. The aforesaid permission has been granted by the Director General of Health Services in

that the first stage trial has been completed and that the drug in question has shown encouraging results in an individual patient who was administered the same over a period of 26 weeks. The aforesaid initiative has also met with the approval of the competent authorities for the second and third phase clinical trials and 9 sites have also been duly identified. 54 children are stated to have been enrolled for the purposes of those trials. The issue which however appears to arise is the funding of expenses which would be incurred in these clinical trials in which 54 children with rare diseases already stand enrolled. The learned Amicus Curiae apprises the Court that the treatment would entail an outlay of at least Rs. 20 lakhs in the manufacture of doses for each enrolled child.

- 4. It would be pertinent to note that in the order of 01 June 2022, the Court had taken note of the Office Memorandum of 19 May 2022 which had enhanced the earlier limit of financial support and increased it from Rs.20 lakhs to Rs.50 lakhs. The said Office Memorandum envisages the extension of financial support up to Rs.50 lakhs for treatment of patients suffering from any of the rare diseases catalogued in the National Policy for Rare Diseases, 2021. The permission which has been accorded for the clinical trial of the experimental drug is in respect of DMD which has been duly recognized as one of the rare diseases in the National Policy.
- 5. The Court is of the considered view that the financial support which is envisaged in the Office Memorandum of 19 May 2022 and its terms which speak of financial aid "for treatment" could be considered as covering the expenses likely to be incurred in the course of administration of the trial

drug by the competent authority in the Union Government. The imperatives for favorable consideration and exploration of this line would be guided by the stark difference in the price of the trial drug when compared to that of other experimental remedies currently available as well as the possibility of the drug which has been indigenously developed then being adopted for treatment of many more DMD afflicted children in our country and across the globe. Apart from the evident benefits of cost saving, the trials may perhaps lead to the rollout of a readily accessible drug for DMD in the country itself.

- While the Court is conscious that the drug is to presently go through a 6. rigorous clinical trial in order to gauge and ascertain its efficacy, it also bears in mind and weighs in consideration the opinion of AIIMS which had informed the Court that the drugs currently being adopted for treatment "may help in attenuating the decline in cardiac and respiratory functions". That expert body had further submitted before the Court that presently there is a dearth of evidence which may suggest or establish that the administration of those drugs would help in stopping the progress of the degenerative disorder. Admittedly, even for those exorbitantly priced drugs there are no long-term clinical studies available and they thus all so remain in the realm of experimental therapies. All of the aforesaid factors would thus merit consideration of the competent authority in the Union Government which may examine whether the expenses which are likely to be incurred in the course of administering the drug to the 54 enrolled patients would stand covered under Office Memorandum of 19 May 2022.
- 7. The aforesaid would in any case be in addition to the Rare Diseases Cell in the Department of Health and Family Welfare in the Union

Government duly attending to the indents which have been forwarded by AIIMS on 01 August 2022 in respect of children who are not enrolled in the clinical trials and are to undergo treatment in terms of alternatives presently available at the various Centers of Excellence.

8. Mr. Chetan Sharma, learned ASG, is thus requested to obtain instructions with respect to the issues flagged above and more particularly with regard to the Office Memorandum of 19 May 2022 being applied to meet the expenses likely to be incurred in the second and third phase of clinical trials of the experimental drug and the treatment of children enrolled in those trials.

9. List again on 09.09.2022, at 2:15 P.M.

YASHWANT VARMA, J.

**AUGUST 5, 2022** 

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